

1. Table of Contents

1	Short Notes	1
2	Minutes	2
3	Detailed anonymised Minutes	4

1 Short Notes

Key Topics:

- **Meeting Introduction:** Yanis and Stephanie introduced the meeting, emphasizing the importance of confidentiality and anonymity. They explained that the session would be recorded for content analysis and later deleted. They also mentioned the use of WhatsApp for communication and feedback.
- **Participant Motivations:** Charlotte, Valentina, and Nefeli shared their motivations for participating in the project. Charlotte wants to help people with similar diseases, Valentina aims to improve pediatric care, and Nefeli seeks to understand her condition better and integrate it into her lifestyle.
- **Medical Care Experiences:** Charlotte, Valentina, and Nefeli discussed their experiences with medical care. Charlotte and Valentina felt that doctors often did not understand their pain and mental health effects, while Nefeli emphasized the importance of being informed about her condition and treatments.
- **False Hopes and Deceptions:** Valentina and Nefeli shared their experiences with false hopes and deceptions from doctors regarding treatments. Valentina mentioned being promised effective treatments that did not work, while Nefeli discussed the impact of doctors' promises on her expectations and pain management.
- **Active Participation in Disease Management:** Nefeli expressed the importance of being active in managing her disease and integrating it into her lifestyle. She emphasized the need for better information and understanding of her condition to make informed decisions about treatments.
- **Research and Information Gathering:** Charlotte, Valentina, and Nefeli discussed their efforts to research and gather information about their diseases. They used various sources, including the internet, books, and medical professionals, to understand their conditions better.
- **Non-Pharmacotherapy Treatments:** Nefeli shared her experience with non-pharmacotherapy treatments, such as physiotherapy and electrostimulation, to manage her pain. She emphasized the importance of trying different alternatives and evaluating their effectiveness.
- **Suggestions for Future Meetings:** Participants suggested discussing how they communicate their experiences to people who do not know about their conditions and how they navigate their daily lives with rare diseases. They emphasized the importance of understanding and support from others.
- **Meeting Conclusion:** Stephanie and Yanis concluded the meeting by thanking the participants for their contributions. They mentioned the next meeting date and encouraged participants to share their ideas and suggestions through WhatsApp.

2 Minutes

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Meeting notes:

- **Participants' Motivation:** Charlotte and Valentina shared their motivations for participating in the project, emphasizing their personal experiences with rare diseases and the desire to make a positive change for others.
 - **Charlotte's Motivation:** Charlotte shared that her motivation for participating in the project stems from her personal experiences with trauma and frequent hospital visits due to her rare disease. She expressed a desire to help others who face similar challenges.
 - **Valentina's Motivation:** Valentina explained that her motivation is similar to Charlotte's, driven by her own experience with a rare disease since the age of three. She emphasized the importance of making a positive change in pediatric care for rare diseases to prevent others from going through the same difficult experiences.
- **Medical Care Experiences:** Valentina and Charlotte discussed their experiences with medical care, highlighting the lack of effective solutions and the feeling of not being listened to by doctors.
 - **Valentina's Experience:** Valentina described her frustration with the medical care she received, noting that while she had a good doctor, there were often no effective solutions provided. She felt that her concerns were not always listened to, leading to feelings of frustration and stress.
 - **Charlotte's Experience:** Charlotte shared her difficulties in trusting doctors due to her rare disease being initially dismissed as psychological. She emphasized the importance of being listened to and the challenges she faced in getting a correct diagnosis and effective treatment.
- **Confidentiality and Communication:** Yanis explained the importance of confidentiality in the project and the need for direct communication through platforms like WhatsApp or Slack.
 - **Confidentiality Importance:** Yanis highlighted that maintaining confidentiality is crucial for the project, ensuring that discussions remain private and are not shared outside the group. This is to protect personal information and encourage open communication.
 - **Preferred Communication:** Yanis mentioned that participants preferred direct communication methods such as WhatsApp or Slack over emails, as indicated by the feedback from the survey. This preference aims to facilitate more immediate and effective communication.
- **Feedback and Participation Rules:** Yanis outlined the rules for participation, emphasizing the need for feedback summaries after each session and the importance of respecting personal information.
 - **Feedback Summaries:** Yanis explained that feedback summaries would be provided after each session to ensure that participants' inputs are accurately captured and to allow for any necessary corrections or additions.
 - **Respecting Personal Information:** Yanis stressed the importance of respecting personal information shared during the sessions, advising participants to avoid sharing very personal details to maintain confidentiality and privacy.
- **Nefeli's Experience:** Nefeli shared her experience with arthritis, describing the initial misdiagnosis and the ongoing pain despite medication.

- **Initial Misdiagnosis:** Nefeli recounted her experience of being misdiagnosed with growing pains for years before being correctly diagnosed with arthritis at the age of 14. This misdiagnosis led to prolonged pain and confusion.
- **Ongoing Pain:** Despite receiving medication for arthritis, Nefeli continues to experience pain, highlighting the challenges of managing her condition and the impact on her daily life.
- **Deception and False Hopes:** Valentina and Nefeli discussed the false hopes given by doctors regarding treatments and the frustration of not seeing improvements.
 - **Valentina's False Hopes:** Valentina shared her experience of being given false hopes by doctors who promised that new treatments would work, only to find that they did not, leading to frustration and disappointment.
 - **Nefeli's False Hopes:** Nefeli described how doctors' reassurances that her condition would improve by a certain time were not met, resulting in ongoing pain and a sense of betrayal.
- **Importance of Patient Voice:** Charlotte and Valentina emphasized the need for doctors to consider patients' opinions and experiences, not just clinical data.
 - **Charlotte's Perspective:** Charlotte emphasized that doctors should listen to patients' experiences and consider the mental and emotional impacts of diseases, not just clinical data. She stressed the importance of patients asking questions and being informed about their conditions.
 - **Valentina's Perspective:** Valentina highlighted the need for doctors to take into account the patient's perspective on how treatments affect their daily lives, not just relying on clinical assessments of inflammation or other symptoms.
- **Research and Understanding:** Nefeli, Valentina, and Charlotte discussed their efforts to research and understand their diseases, highlighting the challenges of finding trustworthy information.
 - **Nefeli's Research:** Nefeli shared that she extensively researched her condition to understand it better and to find ways to manage her pain. She emphasized the difficulty of finding reliable information and the importance of being well-informed.
 - **Valentina's Research:** Valentina, diagnosed at a young age, expressed her ongoing efforts to learn about her disease, driven by her aspiration to become a doctor. She uses various sources, including medical trials and books, to stay informed.
 - **Charlotte's Research:** Charlotte described how her doctor initially explained her disease with drawings, which helped her understand it. She later conducted her own research for a school project, seeking trustworthy sources to learn more about her condition.
- **Non-Pharmacotherapy Treatments:** Nefeli shared her experience with non-pharmacotherapy treatments like Pilates and physiotherapy, and the importance of evaluating their effectiveness.
 - **Pilates and Physiotherapy:** Nefeli discussed her use of Pilates and physiotherapy to manage her arthritis pain. She emphasized the importance of trying different non-pharmacotherapy treatments to find what works best for her.
 - **Evaluating Effectiveness:** Nefeli explained that she kept a diary to track the effectiveness of various treatments, noting how her body responded to each one. This helped her determine which treatments were beneficial.
- **Future Meeting Topics:** Participants suggested discussing how they experience their conditions in everyday life and how they communicate their experiences to others.

- **Everyday Life Experiences:** Nefeli suggested discussing how participants manage their conditions in their daily lives, including interactions with people who are unaware of their diseases.
- **Communicating Experiences:** Charlotte and Valentina agreed that it would be valuable to discuss how they communicate their experiences and conditions to others, especially when dealing with uncommon diseases and varying reactions from people.

Follow-up tasks:

- **Feedback Summary:** Send a short feedback summary after each session to allow participants to check for understanding and provide corrections if needed. (Stephanie)
- **Questionnaire Link:** Update and share the questionnaire link with additional questions for feedback on the first meeting. (Stephanie)
- **Next Meeting Topics:** Discuss how participants experience their condition in everyday life and how they communicate their symptoms to people who do not know about their condition. (Stephanie)
- **WhatsApp Group:** Create a WhatsApp group to share ideas and suggestions for discussion topics between meetings. (Francesco, Stephanie)

3 Detailed anonymised Minutes

Meeting Date: 21 February 2025

Duration: Approximately 1 hour 17 minutes

1. Participants' Motivations

• Personal Experiences as Drivers:

Several participants shared that their involvement in the project is rooted in personal experiences with rare diseases. They emphasized the emotional and physical challenges of frequent hospital visits, early trauma, and the difficulties of managing a condition from childhood. One participant mentioned having dealt with the disease since early childhood, which reinforced the desire to improve pediatric care and support others facing similar challenges.

• Commitment to Improving Care:

Motivations were linked to a deep commitment to effect positive change in healthcare. Participants expressed that their engagement was not only personal but also aimed at ensuring that future patients receive more empathetic and effective care.

2. Medical Care Experiences

- **Challenges in Diagnosis and Treatment:**

Participants discussed difficulties in obtaining timely and accurate diagnoses. One account detailed how early symptoms were dismissed as psychological or attributed to growing pains, leading to prolonged periods of unmanaged pain and uncertainty.

- **Feeling Unheard and Misunderstood:**

Several members described experiences where their concerns were minimized by healthcare professionals. This led to frustration, stress, and a growing mistrust in the medical system, especially when false reassurances were given regarding treatment outcomes.

- **False Promises and Treatment Disappointments:**

There was a consensus that doctors sometimes offered overly optimistic expectations about new treatments. When these treatments failed to deliver the promised improvements, it resulted in feelings of disappointment and betrayal.

3. Confidentiality and Communication Protocols

- **Strict Confidentiality:**

The importance of maintaining confidentiality was strongly emphasized. All discussions are to remain within the group to protect personal information and encourage honest sharing.

- **Preferred Communication Channels:**

Feedback from the group indicated a strong preference for direct communication methods (e.g., WhatsApp, Slack) over traditional email. These platforms are seen as more immediate and conducive to open dialogue.

4. Feedback and Participation Guidelines

- **Structured Feedback Summaries:**

It was agreed that a concise feedback summary would be circulated after each session. This summary will capture key points and allow participants to review, correct, or add to the record as needed.

- **Respect for Personal Information:**

Guidelines were reiterated to encourage sharing of experiences without disclosing highly personal or sensitive details, ensuring that the safe and confidential nature of the group is maintained.

5. Experiences with Disease Management and Research

• Misdiagnosis and Ongoing Health Challenges:

One participant recounted a long struggle with misdiagnosis—initially being told that growing pains were responsible—until a later, correct diagnosis of arthritis was made. Despite treatment, the persistence of pain remains a significant issue.

• Emotional Impact of Medical Interactions:

Discussions highlighted how inadequate communication and the failure to address both physical and mental health aspects have negatively affected patient trust. There is a clear need for healthcare professionals to validate the subjective experiences of patients.

• Self-Initiated Research:

Participants described extensive efforts to research their conditions using various sources (including internet resources, books, and clinical trial data). These self-guided investigations are used to better understand treatment options and the overall evolution of their diseases.

6. Non-Pharmacological Approaches

• Exploration of Alternative Therapies:

There was significant discussion around the use of non-drug treatments such as physiotherapy, Pilates, and other complementary therapies.

• Monitoring Treatment Effectiveness:

One participant highlighted the importance of tracking the response to various interventions (for example, through maintaining a diary), which aids in evaluating what is effective in managing symptoms and overall quality of life.

7. Future Meeting Topics

• Everyday Life Experiences:

Participants expressed interest in discussing how their conditions affect daily interactions and community engagement, including managing the challenges of communicating about a rare disease to those who are unfamiliar with it.

• Enhancing Patient-Doctor Communication:

There is a strong call for exploring strategies to ensure that the patient's voice is heard in clinical settings. Future discussions may focus on how to empower patients to share their experiences and how healthcare professionals can integrate these insights into treatment plans.

- **Clinical Trial Feedback:**

Another topic for future meetings is the process of clinical trials and how patient feedback on new treatments can be systematically captured and integrated into decision-making.

Follow-Up Actions

- **Feedback Summary Distribution:**

A short summary of each session will be sent out promptly to allow participants to verify and refine the record of discussions.

- **Updated Questionnaire:**

The questionnaire link will be updated with additional questions based on the session's feedback and shared with the group to capture further insights.

- **Planning Future Discussions:**

The next meeting will include a focused discussion on daily life experiences and communication strategies regarding the management of rare diseases.

- **Establishing a Dedicated Communication Group:**

A WhatsApp group will be set up to facilitate the exchange of ideas and suggestions between sessions.

These minutes now offer a more comprehensive and detailed record of the meeting discussions while ensuring all personal identifiers remain anonymous.